

eHealth Consumer Interests Workgroup: Draft Timeline

Charge	Draft Recommendations	Discussion Date (proposed)
Identify HIE and HIT outcomes that are highest priority from the consumer perspective	<ul style="list-style-type: none"> Adopt Markle Foundation <i>Consumer and Patient Principles for System Design (MCP 1-7)</i> Make health information available for surveillance and other public health purposes (Text to be drafted) 	June 23
(5b) Make recommendations on whether health information with special protections will be included in electronic health data exchange and potential limits required on the use and disclosure of information pertaining to:		July 12
<ul style="list-style-type: none"> Mental health 		July 12
<ul style="list-style-type: none"> Alcohol/drug abuse treatment 		July 12
<ul style="list-style-type: none"> Communicable disease 		July 12
<ul style="list-style-type: none"> Genetic testing 		July 12
<ul style="list-style-type: none"> Adoption 		July 12
<ul style="list-style-type: none"> Developmental disabilities 		July 12
(5a) Define acceptable and unacceptable data use policies for oversight purposes, including:		July 28
<ul style="list-style-type: none"> Public health 		July 28
<ul style="list-style-type: none"> Research 		July 28
<ul style="list-style-type: none"> Maintaining privacy/security 	<ul style="list-style-type: none"> Adopt (<i>MCP6</i>): Electronic health data exchanges must protect the integrity, security, privacy, and confidentiality of an individual's information. Adopt (<i>MCP4</i>): Individuals should receive easily understood information about all the ways that their health data may be used or shared. 	July 28
<ul style="list-style-type: none"> Patient consent/use of data 	<ul style="list-style-type: none"> Adopt (<i>MCP2</i>): Individuals should be able to decide (i.e., authorize) when their health data are shared, and with whom. Adopt (<i>MCP3</i>): Individuals should be able to designate someone else, such as a loved one, to have access to and exercise control over how their records are shared. Adopt (<i>MCP5</i>): Individuals should be able to review which entities have had access to their personal health data. 	July 28

Charge	Draft Recommendations	Discussion Date (proposed)
<ul style="list-style-type: none"> ▪ Patient opt out provisions 	<ul style="list-style-type: none"> ▪ Adopt (<i>MCP2</i>): Individuals should be able to refuse to make their health data available for sharing (i.e., opt-out). 	July 28
<ul style="list-style-type: none"> ▪ Patient access of own data 	<ul style="list-style-type: none"> ▪ Adopt (<i>MCP1</i>): Individuals should be able to access their health and medical data conveniently and affordably. 	July 28
(5c) Identify specific legal actions required for the priorities recommended by the clinical work team, including:		August
<ul style="list-style-type: none"> ▪ Whether statutory/regulatory amendments are needed 		
<ul style="list-style-type: none"> ▪ Practical, non-technical strategies and solutions for HIE that ensure secure and confidential exchange 	<ul style="list-style-type: none"> ▪ Adopt (<i>MCP7</i>): Independent bodies, accountable to the public, should oversee the electronic health data exchanges. No single stakeholder group should dominate these oversight bodies. Consumer representatives selected by their peers should participate as full voting members. 	
(1) Identify outcomes/options that meet consumer expectations/prepare consumers to manage their own care and advocate for themselves		September
(3) Define recommended guidelines and real-world examples that clarify how data sharing can balance patient privacy and system security with sharing information to improve patient-centered care		October
(1) Understand consumer expectations regarding electronic health data exchange		Ongoing (Sept. listening session)
Review draft of consumer interests section of eHealth Action Plan (drafted by staff)		October
Submit final draft of consumer interests section of eHealth Action Plan to eHealth Board		November 14